

## Posters

## 15. Nursing/Psychosocial issues

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**[346] A qualitative study to explore factors that impact adherence to aerosol therapy in young people with CF: Patient and parent perspectives**

D. O'Toole<sup>1</sup>, G. Latchford<sup>1,2,3</sup>, A. Duff<sup>3,4</sup>, R. Ball<sup>4</sup>, P. McCormack<sup>5</sup>, P.S. McNamara<sup>5</sup>, K.W. Southern<sup>5</sup>, K.G. Brownlee<sup>4</sup>. <sup>1</sup>University of Leeds, Leeds Institute of Health Sciences, Leeds, United Kingdom; <sup>2</sup>Leeds Teaching Hospitals NHS Trust, Adult Regional CF Centre, Leeds, United Kingdom; <sup>3</sup>Leeds Teaching Hospitals NHS Trust, Department of Clinical and Health Psychology, Leeds, United Kingdom; <sup>4</sup>Leeds Teaching Hospitals NHS Trust, Paediatric Regional CF Centre, Leeds, United Kingdom; <sup>5</sup>University of Liverpool, Department for Women's and Children's Health, Liverpool, United Kingdom

**Objectives:** Adaptive Aerosol Delivery (AAD) technology enables accurate measurement of adherence to nebulised therapies, which is known to be variable. This study explored the influences on this from the perspectives of young people with CF and their parents.

**Methods:** Young people with CF with adherence ranging from good to poor were purposively selected. They and their parents were interviewed separately with AAD adherence data from the previous week used to stimulate discussion of factors that influenced episodes of good and poor adherence. Transcripts were analysed using grounded theory.

**Conclusion:** 6 young people with CF (mean age 13, range 11–16) and 6 parents (5 mothers, 1 father) were interviewed. Parent/patient data were analysed separately. Themes included;

1. practical hurdles to adhering to aerosol therapy within the broader context of CF (e.g. interdependence of treatments and the strategies adopted),
2. everyday family life issues (e.g. problems adhering when away from home),
3. the importance of peer groups and
4. the relationship between parent and child.

Emotions and beliefs about treatment impact on all aspects of adherence. One focus was transition of responsibility from parent to child, and parents' unease at perceived loss of control. Analysis revealed similar themes for both adolescents and parents, but often from different perspectives. Teams need to consider the wider context in which aerosol therapy is managed, particularly how it interacts with and impinges upon other treatments, family events and peer groups. Parent and child have different views of treatment and how to manage it. Both need to be addressed if good adherence is to be supported.

**[347] Team insights into adherence barriers: Learning from diabetes self-management exercise**

A. Milne<sup>1</sup>, R. Attfield<sup>2</sup>, S. Thornton<sup>1</sup>, S. Jones<sup>2</sup>, M. Wildman<sup>1</sup>. <sup>1</sup>Northern General Hospital, Adult Cystic Fibrosis Centre, Sheffield, United Kingdom; <sup>2</sup>Sheffield Teaching Hospital, Department of Psychological Services, Sheffield, United Kingdom

**Objectives:** Non-adherence in Cystic Fibrosis has a major impact on survival but is often poorly understood by the Multi-disciplinary team (MDT). We aimed to increase the MDTs awareness of non-adherence by an exercise where the MDT undertook a diabetes self-management exercise.

**Methods:** The MDT received a 2 hour training session in blood sugar measurement and carbohydrate counting and then undertook diabetes self-management for 14 days. Their performance was measured by recordings in a food diary and qualitative interviews investigated their resultant understanding of barriers to adherence.

**Results:** See the table.

Table: Intended and observed adherence

	Blood glucose monitoring	Food Diary completion	Insulin estimation	Carbohydrate counting	Overall performance
Intended adherence	80%	80%	67%	67%	73%
Observed adherence	56%	62%	48%	46%	53%
Discrepancy	−24%	−18%	−20%	−31%	−20%

**Conclusion:** MDT members over estimated their ability to adhere to a diabetes management regime. Barriers they identified lay within the domains of capability, opportunity and motivation. Participants recognised that adherence is a major challenge for patients and that the challenges are common to human beings trying to form habits rather than simply a characteristic of patients with Cystic Fibrosis. MDT members identified time constraints as a major barrier to adherence and considered that support to form routines might improve adherence.

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**[348] From rescue to prevention: Collaborative social marketing project developing posters to promote adherence for nebulised therapy in adults with cystic fibrosis**

S. Jones<sup>1</sup>, N. Babiker<sup>1</sup>, E. Field<sup>1</sup>, J. Royle<sup>1</sup>, M. Wildman<sup>2</sup>. <sup>1</sup>Sheffield Teaching Hospital, Department of Psychological Services, Sheffield, United Kingdom; <sup>2</sup>Adult Cystic Fibrosis Unit, Northern General, Sheffield, United Kingdom

**Objectives:** Adherence to preventative treatment is crucial to minimising the need for rescue therapy with intravenous antibiotics. Changing behaviour requires individuals to perceive a discrepancy between the status quo and an imagined future. We aimed to promote discrepancy and motivate patients to take their preventative inhaled therapy. We used a qualitative approach to explore images and concepts that patients felt increased motivation to adhere. Barriers to adherence were explored using the COM-B model (Michie 2011).

**Methods:** Preliminary ideas generated by the CF team were used to produce outline poster designs. (step mandated by ethics that required poster vetting prior to patient involvement). Purposive sampling was used to identify 12 patients (high, medium and low adherence on basis of I-Neb download data) who were interviewed using the draft posters to understand how posters might promote adherence and to prompt patients to generate their own poster formats. The posters were then revised and further posters produced using concepts arising in the interviews. Patients were then interviewed again.

**Results:** Patients tended to prefer aspirational posters that demonstrated the benefits of good adherence whereas the MDT tended to prefer posters that highlighted the consequences of non-adherence. Patients preferred themes that included real people living "normal" lives. Exploration of barriers to adherence emphasised the importance of establishing and maintaining routine.

**Conclusion:** Posters have the potential to support adherence to preventative therapy as one aspect of a multi-faceted intervention.

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**[349] The ceremonial order of the CF clinic: Time for a new model of partnership?**

K. MacDonald<sup>1</sup>. <sup>1</sup>Queen Margaret University Edinburgh, Health Sciences: Nursing, Edinburgh, United Kingdom

**Objectives:** To explore partnership in the "expert" CF patient's interactions with health care professionals in the CF team.

**Methods:** 30 out-patient consultations between 10 young people (18–34 yrs) with cystic fibrosis and the health care professionals (HCPs) with whom they interact (nurses, drs, physiotherapists, dieticians, psychologists, and a pharmacist) were observed. Following consultations young people and HCPs were interviewed separately to gain further insight into their perceptions of partnership. Data was analysed using thematic analysis. One theme; Asymmetry, is discussed here.

**Conclusion:** Consistent with the published literature in the dr/patient relationship is the *absence of symmetry* in these observed consultations. Rarely do patients make demands or challenge decisions, yet it is clear that sometimes patients come with an agenda which is not openly voiced. Rather they follow the conventional question and answer route which is professionally led and operates in a system of cues rather than explicitly concerned issues. This system results in frustratingly longer consultation times for patients and repetitious questions from different members of the CF team. There is heavy emphasis on checking and rechecking of compliance throughout the consultation.

Finding a balance between paternalism and patient autonomy may require a shift to a new model of patient-led agendas in the clinic setting, but is associated with tensions such as professional accountability. This will not be for everyone, but in expert patients with an established long term condition, it may prioritise their issues quickly, avoid repetition, and save time for all concerned.